MAP to Action: Data Session
Breakout Room Summary
January 27, 2023

Theme 1: Collecting and accessing timelier, more aligned data across the perinatal period	**Theme 2: Collecting and using patient reported data for meaningful improvement**
What messages/ideas/information from the presentations resonated with you?	
• The timeliness of data is important. Although we may be looking at older numbers, sometimes it is outside of our control. But, once the data is collected, we need a faster process to get it released. If the data cannot be released quickly enough, we should at least publish the recommendations. • Find ways to publicly share that are more accessible to non-experts. • Request for more information on how the MMRC is collecting/reviewing data re substance misuse, SDOH. • Raised the need to implement the "Utah Criteria" to understand conditions that are exacerbated by pregnancy (some of the cases we see as pregnancy-associated are really pregnancy-related). • Raised need for updated support/definitions for suicide/homicide to be seen as pregnancy-related conditions.	• Irth connects to the work being done by UniteUs related to connection to SDOH. Health equity is important to us. • Responses (in the Irth App) show that there is a lot of stereotyping – like asking a Black person if they are on WIC. This is a frequent piece of feedback given. • Importance of saying something happened and then following it up with how many times it happened (with data). • When stories are shared, there needs to be next steps with data, for leadership to be called on to respond. Accountability is needed. • Need for tools to help us tell stories. Broad and easily accessible for community members. They need to be able to say how they want their stories told. Some tell their stories over and over again with no action taken.
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How does data support your work? Are you engaged in a project that relates to this work?	
• Would like advice/ideas on how to "how can we use the data to change policy?" • Even data may be similar year over year, it needs to be presented in consumer friendly easier to understand. • Examples shared: "Count the Kicks" is a campaign encourages women to the count the kicks from their baby. An App you can download. Another example was how obesity is a risk in pregnancy. How do we get providers/others to relay the information and educate in accessible way? • Data needs to be made accessible to people who don't like data or who don't use it. This is the true essence of the grassroots effort: making information accessible. Doing so affects policy, because we can get a wider range of people familiar with the issue.	• Irth is not currently being used within in NJ but there is the need is great. • Learned from Irth that each state is unique. The tool is very community-oriented, and the aggregate knowledge isn't transferable because it is linked to community. It looks at what are the specific behaviors. Are hospitals following baby-friendly protocols? With data we can see what protocols are not being followed. • There is a framework in which work is done for the Black community (https://blackmamasmatter.org/our-work/toolkits/). The absence of Black-led models in the care we are delivering is troubling. We should be utilizing the Black Mamas Matter framework to collect and extract data. We are not using Black led organizations to lead and do this work. (Additional background- https://blackmamasmatter.org/literature/)

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Thinking forward – how would you measure success in data collection, use, and reporting?	
(Not discussed- lack of time)	• Better understanding about what happens before and after the hospital for birthing people. • How can we change lags in data? • What can we do to aggregate data? • How is data from FQHCs included? • Pregnant people are not always interested in providing responses to surveys. • Breastfeeding is often overlooked. We would love to see more data about what's happening in communities even before pregnant people get to the hospital. NJ breastfeeding strategic plan is being updated with good data from around the state. • UniteUs is working on the Healthy Women Healthy Families initiative and working with social care providers, trying to determine reasons for missed care: are women not getting to the doctor because of public transportation for example? They are trying to reduce the trauma of telling your story repeatedly by using data.
In thinking about this topic, what has held you back from this work or a specific project (resources, finances, connection and support from other partners, uncertainty about where to start, etc.)?	
(Not discussed- lack of time)	• Much of the work being elevated in New Jersey is from white-led organizations and white leaders, with its intended purpose to change birth outcomes for Black and brown people. This is a state where there are Black clinicians, advocates, and organizations doing this work and living this experience who should be given the opportunity and the resources to lead. Instead of consistently offering the opportunities to white-led established organizations, there is a place for those organizations to be engaged but the need is great to have this work led by black-led CBOs and those who have a deep understanding of the needs to have a greater impact in New Jersey. • NJ is focused on doing things our own way and recreating the wheel. There has been excellent work done in other states like CA that have worked for the Black and brown community like implementing standard protocols for care. Our state is not strong in that space- we still have hospitals that don't have any protocols in place. • Irth focuses on transparency of our reviews, not just giving them privately to a hospital. Honesty must be at the root of what we're doing. We can't let a lack of

	transparency be an obstacle to those who can get the work done. - We need to get comfortable having uncomfortable conversations. Every statistic is a life, a family, a community impacted. We need to stop looking at individuals as diagnoses or illnesses and see them as human.